

SLOW GUTS AND POLIO SURVIVORS

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<<I have trouble swallowing but no one believes me. Food doesn't get stuck in my throat, but seems to lodge somewhere behind my breastbone. I had a normal swallowing study and the doctor doesn't believe I have a problem. But, food sticks and it hurts when it does! Do other polio survivors complain about this?>>

They surely do. It's hard enough to "swallow" having PPS without doctors refusing to believe you're having trouble swallowing. It's true that most Post-Polio Institute patients report having only occasional, mild problems swallowing. The problem is usually high in the throat: not being able to get down pills, largish pieces of meat and, maybe even more often, difficulty clearing their own secretions. A barium swallow study (where you eat and drink food containing barium and "video" is taken with an X-ray camera) usually shows mild muscle weakness in the throat or sometimes, as in your case, no problem at all. This "negative" finding is just like a muscle test of an arm or leg not showing weakness in the doctor's office, even though you feel weaker or even stumble at the end of the day as you get more tired.

Polio survivors also have swallowing problems below the throat. What you describe -- food getting stuck behind your breastbone in the esophagus (the tube connecting the throat to the stomach) is not

uncommon in polio survivors. The muscles of the throat and esophagus should contract in a coordinated sequence, like a snake, to move the food downward and into the stomach. Food gets stuck when the esophagus doesn't contract and its muscles go into spasm, not unlike when back muscles go into spasm when your leg muscles are too weak to hold you up. Food usually gets stuck right behind the top of the breastbone. And, yes, stuck food is painful...and scary! Even if food does make it down to the bottom of the esophagus, in some polio survivors the "valve" at the bottom of the esophagus doesn't open and prevents food from entering the stomach, a condition called achalasia.

Why do polio survivors have trouble with muscles from their throats to their stomachs? Fifty years ago, Dr. David Bodian discovered that every polio survivor had some damage to neurons in the brain stem, the so-called "bulb" of the brain. When brain stem damage was severe and "breathing neurons" stopped working, "bulbar polio" was diagnosed. But the most common bulbar polio symptom was trouble swallowing not trouble breathing, because the poliovirus also damaged the bulbar neurons that control the vagus nerve, the nerve that activates and coordinates muscles from your throat down to your stomach.

Unfortunately, 99% of gut doctors have never seen food get stuck in the esophagus and don't know what to do about it. We've found that a low dose of the muscle relaxants Klonopin and Bentyl, taken 30 minutes before eating, can relax the esophagus and allow food to slide down to its intended destination.

But wait! There's more! Vagus damage likely explains our first Post-Polio Survey finding that diarrhea, colitis, ulcers and constipation are as much as six times more common in polio survivors than in the general population. Some polio survivors report that their stomachs don't empty, a condition called gastroparesis. Others have their intestines abruptly stop moving --

as a side effect of medication, after surgery, a gall bladder attack, or for no reason at all -- a condition called paralytic ileus. Often, the muscles of the stomach and intestines get moving again on their own. But, sometimes the drug Reglan is needed to jump-start the stomach and intestines. Reglan can have bad side effects, since it enters the brain. DOMPERIDONE, a drug that does not enter the brain (or the US, so you have to buy it from Canada) is the better choice if you can take it by mouth). Also, polio survivors need to try to prevent gut slowing by being careful when taking drugs that are anti-cholinergic (drugs that have dry mouth as a side effect) since they block the activity of the vagus nerve.

Finally, polio survivors who have a chronic sore throat, husky voice, or burning in the chest should be evaluated for reflux by an ENT doc, who'll look at the upper throat and vocal cords, and a GI doc, who may do a gastroscopy to look down your esophagus and into your stomach. If you have a gastroscopy, make sure that the doctor goes light on the anesthesia and uses the anesthetic Propofol, since it's short-acting and allows polio survivors (usually) to wake quickly (see http://www.postpolioinfo.com/lib_surgical.php).

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ADDENDUM: CONSTIPATION NATION?

Polio survivors have slow guts, thanks to poliovirus-damage to the vagus nerve (see above) that should fire to move food from your mouth all the way through to the other end (see articles in The Post-Polio Library at <http://www.postpolioinfo.com>). Here are some things about constipation you may not know:

1) Constipation isn't one thing. Sometimes poo gets stuck in the ascending colon on the right side of your belly, sometimes in the transverse colon across the top of your belly, sometimes in the descending colon on your left side or in the rectum. So, you have to focus treatment where constipation occurs.

2) Not all laxatives work in the same way or in the same place:

> Roughage and Senna irritate the whole colon to make it move;

> Miralax and Colace add water to your poo to "lubricate" the colon;

> Dulcolax stimulates the ASCENDING colon if you get plugged there;

> Psyllium absorbs water and expands to stop diarrhea but also combines with sludge to make one single poo (and not lots of little "rocks") that itself stimulates the colon naturally to make things move. (You should plan to sit on the throne after eating to take advantage of the natural stimulation caused by food in the colon);

> Magnesium supplement may help with moving things along

> Suppositories are for rocks in the lower colon and rectum.

3) If nothing is moving, your stomach isn't emptying or the colon won't respond to the above treatments, there is a great drug -- domperidone (sadly NOT Dom Perignon) -- that directly turns on the muscles that empty the stomach and move the colon.

Domperidone has no side effects and doesn't enter the brain (as does Reglan, which can cause Parkinson's-like shaking and should not be used by polio survivors). Of course, the FDA hasn't approved domperidone even though it's been sold over the counter for 20+ years in Europe for nausea during pregnancy! (Apparently, not enough payola to the FDA.) You CAN get domperidone from Canada with an Rx. BUT domperidone can slow conduction through the heart in some people. So you need an EKG before you start and while you're on it.

So, there's a short course on pushing poo. You may need a combination of treatments or different treatments at different times for different types of constipation.

Keeping a poo diary (quantity, quality and time of day) that includes symptoms and what laxatives you've taken is vital so that you can identify your natural rhythm, where things get stuck and what you need to take to make things work.

Happy eating (and the other thing).